

# Carers Together

How we all fit into the jigsaw  
that is health and social care

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# Carers Together

- Carers Together is a Hampshire wide carer-led organisation established in 1993 to include Hampshire, Portsmouth and Southampton.
- It provides a voice for relatives, friends or neighbours who are caring for, or arranging care for, someone else.
- It represents carers views and needs locally and nationally.
- It is an independent organisation run by carers, with carers and for carers.

# Some Historical facts

In 1998 Carers Together was invited to talk to the Hampshire wide Social Services Committee. We talked about Our Vision:

- Working in Partnership
- Meaningful Consultation
- Independence and Interdependence
- Joint Working
- Realistic financial support
- Real and Equal Representation
- Mutually agreed goal posts
- Recognition, Empowerment, Respect and Consideration
- Best Value and Real choice
- Accurate available and understandable information
- Informed, involved decision making
- Agreed Joint Strategy and Aims

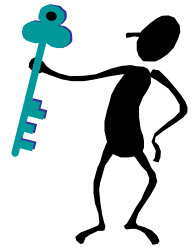
# Some Key Words 1998

## Carers (and service users) need and would like



- Accessibility
- Communication
- Community awareness
- Consideration
- Consultation
- Continuity
- Co-ordination
- Frankness
- Funding
- Independence
- Information
- Interdependence
- Openness
- Partnership
- Representation
- Resources
- Respite
- To be valued

- Choice
- Creative options
- Empowerment
- Equal status
- Equity
- Respect
- Recognition
- Responsive services
- Support
- Training
- Trust
- To be appreciated
- To be consulted
- To be enabled
- To be involved
- To be listened to
- To participate
- To represent themselves



2020

Plus Personalisation?

Plus Coproduction?

# Partnership from a carers perspective 1998

- P** Partnership in planning
- A** Ask us what we want
- R** Respect our views
- T** Two way dialogue
- N** Negotiate with us
- E** Equal partnership at all levels
- R** Recognition
- S** Sharing and caring
- H** Hear what users and carers say
- I** Information
- P** Planning in partnership

# Agreed joint strategy and aims 1998

At the end of the presentation we said:

- We know that Rome wasn't built in a day, and we do not expect all our wishes, hopes or aspirations to be met at once.
- Remember we are very pragmatic and we are used to waiting for what we need and to managing on very small budgets.
- However we hope that some of the suggestions can be considered sooner rather than later and that we are soon all able to take small steps along the path to partnership in action.
- It does seem as though we have a long way to go.

# Who is a carer?

A carer is

- someone who, without remuneration, has the main responsibility for providing or for arranging care for someone else who, because of long term illness, disability, or old age is not able to care for him/herself or
- anyone whose life is affected in any way by the illness, disability, age, frailness or health condition of someone else or
- someone who, without remuneration, has the main responsibility for providing or for arranging care for someone else or
- a person who gives support, help and assistance to a relative, friend or neighbour or
- anyone who provides or intends to provide a substantial amount of unpaid care on a regular basis or

**BUT**

**There is no single, simple way of defining a carer because all carers are different individuals supporting different people with different needs**

# 'One challenge today is the 'supposed definitions' of a carer

- In fact they cannot be definitive because each description is different depending on who you are talking to.
- The label 'carer' is often made to suit the commissioners or providers of services so that the 'carer' fits the service they wish to provide. It is when organisations and commissioners start to look for someone who fits the label that the complications start.'
- Statutory organisations try to put people into identified boxes so they can clearly identify those they will or may help. However the boxes vary and are not the same across all statutory agencies or indeed within a statutory agency.
- If you talk to different people in different authorities, organisations or agencies you find a range of meanings depending on the service division, the funding available and the outlook of the individual professional.
- Many people do not recognise or accept that they are carers



# The word 'carer'

The word 'carer' refers to people who provide unpaid care to a relative, friend or neighbour who is in need of support because of mental or physical illness, old age or disability.

It does not include people who work as volunteers or paid carers; these people should be referred to as 'care workers'.

It is also important to remember that some people who use social services are also 'carers'. For example, many people with learning disabilities provide support to their ageing parents.

**SCIE October 2005**

## **In reality**

**The term 'carer' has now been adopted by the public, care agencies, health and social care as referring to paid care workers**

**So it is very confusing now – 'I cannot count the number of times someone has said what do you do, and when I say I am a carer – they reply who do you work for?'**

# Support for Carers

- ‘If you do not know the questions to ask, it is difficult to find the answers you need’
- ‘If you do not understand or accept the label - help and support may be delayed until you reach crisis’
- Giving people a label is the first step to dehumanising them’
- No single organisation or individual has all the answers for anyone – so commissioning needs to be innovative and flexible, creative and reliable, work in partnership and in coproduction
- Carers Support work should identify and look at carers holistically

# ‘Carers Support can be ‘Direct’ or ‘Indirect’ or ‘Community’

- **Direct Carers Support** - is provided by any organisation, service or group set up specifically to give support to carers. This can be in a range of different formats, methods and services but will have the primary aim of supporting carers.
- **Indirect Carers Support** - is provided by an organisation, service or group, statutory and/or voluntary, set up specifically to give support to people with a specific disability, medical condition or illness but which gives considerable support to carers, deliberately or by default, because of the support they give to the person being cared-for and the networks and information they establish.
- **Community Carers Support** - is provided by a wide range of organisations, services and groups, statutory and/or voluntary, that provide a range of community facilities that carers can tap into as and when needed. These will not be specifically for people with disabilities or carers but will be available to any citizen on a basis of need e.g. Voluntary Services, CAB, Red Cross, waste management, public transport etc.

# Some points to consider

## **Some points to consider:**

- Carers are people first!
- People are individuals with individual needs.
- Carers have a range of needs as people and as carers!
- Some of their caring needs can be met as people, some need specific expertise and caring support.
- How people care is as different as the number of different people in the world.
- Carers can be any age and ability.
- Approximately 1 in 8 people is a carer (that could include an eighth of any workforce), 74% are older people, 75% of older people do not actively receive health and social care support. **It is estimated that the number has increased during the pandemic**

# Suggestions

- We should find out what carers say is most important to them and what would make a difference. (The carers group of the Hampshire Carers Partnership Board has a list of their priorities)
- We should continue to encourage GPs to develop their register of carers – and signposting carers to services that can support them (possibly either through Care Navigators or Social Prescribers)
- Organisations and businesses should be encouraged to identify the carers in their work force and wherever possible offer flexibility and support to help carers remain in work
- Having a Carers Champion in each organisation would help
- Look at the services currently provided and compare them with the list developed by carers over 20 years – what has changed and what impact has the Pandemic had so far?
- Look at other ways communities can support carers – some identified through the Pandemic

# Coproduction

- Coproduction is a reciprocal coproduction of activities by professionals and citizens.
- It shares the planning, design and delivery of services, recognising that both need to contribute equally in order to improve quality of life for people and communities.
- Coproduction helps to ensure that resources are used wisely to develop the services that people really want and need.
- It produces better outcomes for carers and people with lived experience and can help build stronger communities and develop citizenship – working together to make things better

# Coproduction

- Include the people most affected by what you do or are planning to do at the heart of the work – from design to implementation and monitoring
- A culture change for most professionals and people who use services
- Plan for the future – together – use the coproduction checklist
- Services users and carers are everywhere – staff, volunteers often need simple solutions – to achieve major improvements
- Coproduction saves time and money in the long term

Then what next? Service users and carers as leaders?

# Partnership

- Real partnership – not just a tick box
- Best way – not necessarily the old way
- Thinking how to achieve it - equal opportunities, agreeing goalposts, communication
- Using the carer experience and expertise already there
- Things to think about - people/organisations to involve, work together, lots of answers
- Compassionate Communities
- Safeguarding and taking risks – be positive
- What can good housing do? Sheltered, extra care, appropriate to the needs of carers and individuals .....
- Support Planning Partnership
- Carers Partnership – led by carers



# No single organisation or individual has all the answers for everyone

- ‘Carers are all service users’
- Not just health and social care services but a range of services in the community including police, ambulance, fire service, transport, housing, waste disposal, libraries, shops, leisure services, village/community halls services etc.’
- Some organisations e.g. Southern Health, are developing an Active Carers Strategy. They are listening to carers, gathering Carers Stories, making a commitment to improve the experience of carers, have joined the Hampshire Carers Partnership, identified what they need to improve, and are also developing a coproduction strategy.
- Others such as UHS have appointed a Carers Support Worker and are also developing their carers strategy.

# Suggestions

- Surely a good move would be to coordinate all the Strategies so carers are at the centre and ideas and actions can be coordinated?
- Work with HYCA to help find solutions for Young Carers
- Ensure that a Carers Strategy meets the wishes, ideas and suggestions of carers and is a Joint Strategy with other organisations that support carers – so carers are at the heart and their needs are met in a coordinated way
- Ensure there is an Action Plan to help the continuation of positive solutions and the implementation of new services, new and innovative ideas in partnership, personalised and coproductive way

# Suggestion

- ‘Statutory organisations need to change their culture and work in coproduction with carers and people with lived experience, as well as other stakeholders, to ensure they are involved in the development, design and provision of services to meet their real needs.’
- Gather the views from carers and listen to the voices of those with lived experience
- Think about how to harness what is already there, but not yet being maximised for optimum outcomes
- Communicate and work with all the organisations around that support carers e.g. Southern Health, Solent, UHS
- Think about developing a Carers Charter that all organisations can be asked to sign up to

# The Health and Care Jigsaw

- It is held together by carers, and the people they care for - without them, health and community care services would collapse
- Everyone is different - make sure you ask carers the right questions and find person centred answers
- Find out what the carer can do, what are their needs, how they receive help, how they can be supported, how they are treated and respected.
- Don't assume you know what to do - or have all the answers
- Use the carers knowledge and acknowledge they a have a role to play
- Reach out to people in a caring role who do not identify themselves as carers – learn from other initiatives that are happening outside the City
- Do not assume that it is OK just to put information on the Web. It is important to also develop other ways of reaching out

# The effect of the Pandemic

- What has changed due to the Pandemic – for the worse, for the better? Work out how to use the experiences to bring about positive change
- Not being able to visit the person you care for if they are living elsewhere. Why can't a carer be designated a key worker?
- Having a break from caring is essential to enable a carer to carry on caring. It is not a new problem, it has been a priority for carers for many years. It is not the same for each carer as they are all different with different caring responsibilities.
  - Some need regular daily or weekly time off, some manage with 2 hours a week.
  - Some need a period of time away from home to enjoy a relaxing break in a centre that understand their needs.
  - Some want a break from the person they care for others want a break with them
- During the Pandemic, breaks have disappeared or been greatly reduced. How can this be relieved, reinstated or improved in future?
- A number of surveys with useful ideas/suggestions have been published during the pandemic and a survey of carers is currently being undertaken by Healthwatch Hampshire

# Interesting and useful information, documents, resources and books

**Keeping in touch with change** - use all resources including:

- ❖ [www.gov.uk](http://www.gov.uk)
- ❖ [www.parliament.uk](http://www.parliament.uk)
- ❖ [www.nhs.gov.uk](http://www.nhs.gov.uk) and CCG Websites
- ❖ [www.kingsfund.org.uk](http://www.kingsfund.org.uk)
- ❖ [www.carerstogether.org.uk](http://www.carerstogether.org.uk)
- ❖ [www.thinklocalactpersonal.org.uk](http://www.thinklocalactpersonal.org.uk)
- ❖ [www.scie.org.uk](http://www.scie.org.uk)
- ❖ [www.nationalvoices.org.uk](http://www.nationalvoices.org.uk)
- ❖ CQC [www.cqc.org.uk/](http://www.cqc.org.uk/)
- ❖ NICE [www.nice.org.uk/](http://www.nice.org.uk/)
- ❖ DWP [www.dwp.gov.uk/](http://www.dwp.gov.uk/)
- ❖ Carers UK [www.carersuk.org](http://www.carersuk.org)

# Interesting and useful documents and books

## Books, articles, electronic sources e.g.

### ❖ **Carers and their Rights - the law relating to carers**

This guide (7<sup>th</sup> edition) describes the legal rights of carers as they apply in England and Wales. It was written by Luke Clements, Luke Clements is the [Cerebra Professor](#) of Law and Social Justice at the School of Law, Leeds University

<http://www.lukeclements.co.uk/wp-content/uploads/2018/05/7th-ed-draft-Carers-Guide-11.pdf>

### ❖ Care and Support Guidance - <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#using-the-care-act-guidance>

### ❖ **Selfish Pigs Guide to Caring – Hugh Marriot**

### ❖ **Extreme Caring – you have to go on - Stuart Donnan**

### ❖ Carers Together – Key Statements (email [admin@carerstogether.org.uk](mailto:admin@carerstogether.org.uk) – for a copy)

### ❖ Caring Behind closed doors - forgotten families in the coronavirus pandemic - Carers UK

### ❖ Information, Services and Support – in Hampshire and the Isle of Wight during the coronavirus pandemic - Healthwatch Hampshire 25 06 20

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